



## RESEARCH

# Delivering Personalised Home Care for People with Dementia: An Investigation of Care Providers' Roles and Responsibilities

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**Context:** Home care agencies are a critical part of the social care system in England; however, little is known of how they perceive their role in delivering personalised care or their approach to supporting people with dementia.

**Objectives:** To investigate the perception of home care managers of their capacity and capability to provide care for people living with dementia with a focus on specialist care, and the challenges of delivering personalised support.

**Methods:** A qualitative study employing semi-structured interviews (May–October 2018) of ten independent home care managers in England.

**Findings:** Three themes were identified. First, managers aimed to provide responsive care, assessing individual needs and family circumstances, including addressing social and emotional needs in keeping with a model of personalised care. Second, in responding to commissioning processes, managers found prescriptive specifications constrained delivery of responsive home care. Sharing assessment and care planning with commissioning teams helped managers personalise client care but created tensions. Third, workforce preparedness was a priority, with life skills and experience valued above qualifications. Agencies used different service models, with only a few referring to specialist dementia roles or services. However, all were aiming to increase understanding of dementia across their teams as part of their approach to personalisation.

**Limitations:** It was not possible to interview home care workers who may have given alternative viewpoints.

**Implications:** Home care agencies could be supported to deliver personalised home care for people with dementia by taking greater responsibility for assessment and care planning, thus encouraging outcomes that include wellbeing and social goals. Developing a valued and skilled workforce will be essential to achieve this.

**Keywords:** domiciliary care; dementia; home care workers; personalised care

## Introduction

Around two thirds of people diagnosed with dementia remain in their own homes, relying most frequently on home care services funded by the public sector or through their own financial arrangements (Alzheimer's Society, 2016). Dementia, a condition characterised by decline in memory, communication skills, and ability to carry out daily tasks, leaves individuals less able to care for themselves, more prone to emotional and behavioural problems, and at risk of poor physical health (Department of Health, 2009; Nurock, 2017). Due to the variable nature

of the condition, effective home care delivery must be responsive to fluctuating needs to provide appropriate and timely care. Currently there is a gap in understanding how home care agencies provide home support for people with dementia that responds to their personal needs and those of their carers; whether those needs are met as part of generic care, or if services are organised to deliver specialist support for dementia (Davies et al., 2019).

In the early days of establishing care at home, legislation placed a duty on local authorities (LAs) (units of local government with statutory duties of care) to provide home care services (Cm 849, 1989; National Health Service Act, 1977). In England, LAs traditionally undertook assessments of need, and both commissioned and delivered home care services. With the introduction of a market model in the public sector, LAs became enabling institutions, acting as commissioners of services from external providers, rather

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than providers of services (Knapp, Hardy & Forder, 2001). Subsequently, generic policy drivers (e.g., HM Government 2008; Cm 8378, 2012; National Audit Office 2014; National Institute for Health and Care Excellence (NICE), 2015) have advocated a more personalised and flexible approach to the delivery of care. It is now required that service providers deliver 'personalised care' within a person-centred model enabling people to have choice and control over the way their care is planned and delivered based on what matters to them, their individual strengths, and needs (see Health Foundation, 2016; NHS England, 2019a, b; Department of Health and Social Care, 2020).

Most home care is now provided by independent businesses (United Kingdom Home Care Association, 2012). Arrangements for home care can be: requested and paid for by self-funding clients using savings or through a personal budget provided by the LA; commissioned and funded by LA care managers for clients eligible for LA funded care; or co-ordinated by LA staff commissioning care for clients who fund their own care. LA commissioned care often focusses on core activities such as personal care, for example bathing, dressing and medication management. LA commissioned home care has generally been conducted within a fixed budget adopting a time-and-task approach, with services delivered in prescribed time slots, tightly specified and funded by LAs, and focused solely on personal care tasks (NICE, 2014; Bottery, 2018). Conversely, home care that is self-funded may be characterised by the provision of a wider range of care and support activities provided over substantial periods of time. There are, however, real cost implications associated with this approach.

Furthermore, there are implications for home care providers, evident in difficulties with the recruitment, retention, and training of their workforce which have been well-documented (Care Quality Commission, 2018; Jefferson et al., 2018). Vacancy rates of 9% and a turnover rate of almost 38% among care workers inevitably affects care providers' capacity to meet increased demand (Skills for Care (SfC), 2018; Bottery, Ward, & Fenney, 2019). Care work is poorly paid, physically and emotionally demanding, but receives little public recognition (Purvis, 2019; Schneider et al., 2019). For older people with dementia, access to specialist home care services employing appropriately trained staff is a longstanding policy objective (Department of Health, 2009). However, there remains a lack of clarity about how this might be achieved, with uncertainty about whether home care for people with dementia is provided by specialist services, or within generic services delivered by suitably trained staff (Challis et al., 2016).

The provision of home care is frequently complex, delivered in non-clinical domestic settings, dependent on a skilled and adaptable workforce routinely providing relational care (Abrams et al., 2019). It is within this context that home care providers are challenged to provide personalised care, characterised as giving people choice and control over the home care support they receive (NHS England, 2019a, b), within the climate of financial austerity which has particularly affected the funding available for people eligible for LA support over the last decade.

For the growing population of people with dementia living at home, little is known about how home care providers promote personalised care reflecting policy guidance in the daily provision of support at home. It is from this perspective that this paper presents findings from a qualitative study of independent home care providers. The aim was to investigate the perception of home care managers of their capacity and capability to supply care for people living with dementia.

## Method

### *Design and recruitment*

The qualitative study of home care provision was embedded within a larger dementia research programme which had involved the participation of a range of different service providers and organisations that supported people with dementia and their family carers (Chester et al., 2017). Purposive sampling (Palinkas et al., 2015) was used to identify home care agencies in varied demographic locations that had participated in the larger study. This identified 15 home care agencies delivering care across seven LAs in North West England. They were re-contacted to take part in the qualitative study. The intention was to conduct an interview with at least one manager in each of the seven authorities.

Home care providers were emailed or telephoned and invited to take part in the study. The initial contact person was generally the same individual who had assisted and participated in the larger study and tended to be the manager, director or owner. A brief explanation of the study was given, and an information sheet and a summary of interview topics were provided by follow-up email. The information sheet covered aspects of confidentiality, anonymity, and the voluntary nature of participation. All 15 home care agencies were contacted during the fieldwork period. One contact person was on long-term sick leave and four contacts chose not to respond to the invitation emails. The remaining ten home care agencies agreed to take part. These operated across six LAs which included a large metropolitan district as well as smaller urban and rural areas; all delivered care to adults but predominantly to people over 65 years of age.

Verbal consent to participate was sought from each participant. Semi-structured interviews were conducted by telephone (Novick, 2008), offering an efficient and relatively unobtrusive approach to data collection. Telephone interviews were conducted by two experienced qualitative researchers (CS, SA), audio recorded and professionally transcribed. Interviews, which lasted from between 17 and 58 minutes were conducted between May and October 2018. Following the interviews, each participating agency received a £40 voucher to acknowledge the manager's time and contribution.

Ethical approval was granted by the National Research Ethics Service (NRES) (Ref: 15/NW/0822) for the larger study from where home care agencies were initially identified. However, NRES and University Research Ethics Committee review is not required for staff recruited by virtue of their professional role (Department of Health Research and Development Directorate (England), 2011)

or for research involving interviews with participants on subjects deemed to be within their professional competence (University of Manchester, 2016).

### Data Collection

A semi-structured interview guide was developed by the research team drawing on issues raised in policy guidance (e.g., NICE, 2014; Department of Health, 2015), previous research, and knowledge of the sector gained through advisory groups in the research centre. This ensured the inclusion of relevant topics for investigation and enabled the interviewer to follow issues of particular concern to the interviewee and explore emergent themes (**Table 1**). In keeping with a qualitative approach, the questions were open ended and explicitly avoided direct questions about personalisation in asking about delivery of care and staffing. This was to reduce any social desirability bias, and elicit how personalisation was shaping managers' practice and services using their own words.

### Analysis

Each interview transcript was reviewed for accuracy and for any omissions in transcription. A thematic approach (Braun & Clarke, 2006) was used to systematically explore the data to identify salient themes using Atlas ti to support the data management. Three members of the research team (KD, CS, SA) coded the transcripts independently prior to deciding upon codes and themes, applying Braun and Clarke's (2006) six phase process used in thematic analysis (familiarisation, generating codes, identifying themes, reviewing themes, defining themes and interpreting themes). In keeping with the design of the topic guide, the process of coding the data was undertaken without attempting to shape it into a pre-existing coding frame, or the researchers' analytic preconceptions. To assure rigour and accurate interpretation of the findings, discussions of the analysis were undertaken through an iterative process which involved revisiting the themes and the way they were described, reviewing the evidence to support them, and ensuring there was a clear line of sight between the data and the themes identified. The term 'client' used

in this paper matches the terminology most regularly expressed by the managers in their interviews.

### Results

**Table 2** shows the characteristics of the ten home care agencies. Participants operated at managerial level with roles such as care or training manager, and included registered manager, director, and owner. Six agencies were local independent providers, and four were part of national franchise organisations. Four agencies catered almost exclusively to LA funded clients and three almost exclusively to privately funded clients, the remainder providing to a combination of both client types. Care agency size varied considerably ranging from fewer than 60 clients to more than 900 and from fewer than 30 staff in the smallest agency to over 400 in the largest. With regard to the proportion of clients with a diagnosis of dementia or probable dementia, four respondents estimated between 20% and 25%, two around 30% to 33%, one around 40%, and three respondents estimated around 50% of their clients were living with dementia or probable dementia.

Three related themes were identified from the interviews: Aiming to deliver responsive care according to individual needs and family circumstances; commissioning processes influence providers' capacity to deliver personalised care; and preparing the workforce for delivering personalised care (**Table 3**). These are described in detail with brief illustrative quotations in the text. Longer quotations have been included (**Tables 4–6**) to provide further exemplification. Participants are identified in the text as P1-P10.

#### **Theme 1: Aiming to deliver responsive care according to individual needs and family circumstances**

Personalised care includes social and emotional needs, but capacity to provide this varies

The construct of personalised care was a frequent thread running through each of the interviews and was implicit in the language used by the managers. Terminology from social care policy and guidance, such as 'person-centred', 'client-led', 'individualised' or 'tailored', was used by many of the participants to describe the care they delivered.

**Table 1:** Topic guide for home care managers.

Topic areas	Interview questions
<b>Background</b>	Tell me about your organisation: number of clients, staff/home care workers.
<b>Dementia specific care</b>	
Type of care delivered	How many clients have dementia and what arrangements are made specifically for people living with dementia? (level of care, type of care activities, funding arrangements, influences on care arrangements, reviews) What are the particular issues for delivering care for people with dementia and how do you manage this in your organisation?
Staffing	Tell me about the issues you experience regarding staffing care packages for people living with dementia (recruitment issues, qualifications, specialist training for dementia, monitoring quality of care).
Regulations	In what way do regulations/government guidance influence how you provide care for people with dementia?
<b>Closing question</b>	Are there any issues you would like to highlight or add about provision of dementia specific care?

**Table 2:** Home care agency characteristics.

	Job Title	Total no. of clients	% of clients estimated by manager with probable dementia	Number of staff (number of care workers)	Proportion of clients funded by LA or self-funded as reported by home care providers
P01	Director/Registered manager	178	Over 50%	54 (46)	Majority funded by LA
P02	HR manager/In-house trainer	280–290	Around 33%	70 (60)	Majority funded by LA
P03	Manager	168	About 30%	44 (44)	Majority funded by LA
P04	Care manager/Registered manager	58	20%	45 (38)	53% LA, 47% self-funded
P05	HR and Training manager	125–130	About 40%	70 (58)	99% self-funded
P06	Registered manager	930	22%	428 (378)	98% LA
P07	Registered manager/Director	96	25%	56 (40)	60% LA, 40% self-funded
P08	Registered manager	70	About 25%	29 (26)	Two thirds LA, one third self-funded
P09	Head of Client Care	171	About 50%	87 (77)	Majority self-funded
P10	Care manager	64	48–50%	66 (60)	All self-funded

**Table 3:** Themes identified from manager interviews.

Main themes	Subthemes
1. Aiming to deliver responsive care according to individual needs and family circumstances	Personalised care includes social and emotional needs, but capacity to provide this varies Understanding wider family needs as well as individual client needs Collaborative and outreach activities supporting community involvement
2. Commissioning processes influence providers' capacity to deliver personalised care	Prescriptive specifications constrain providers' capacity to supply personalised home care Sharing responsibility rather than duplicating assessment and care planning with statutory services may improve personalised care
3. Preparing the workforce for delivering personalised care	Care roles include training in dementia but relatively few specialist roles exist No fixed model of recruitment, training, or development Valuing staff encourages compassionate care

There were differences in the way managers of LA contracted care described the delivery of personal care. Participant 6 referred to essential care required for daily living, whilst Participant 1 described an approach that included a more “personal touch”:

It's vital care. Daily living, rather than doing the nice bit which is the support work and meeting with people for a few hours. (P6)

... the personal care is not just washing and dressing. We apply make-up. We style their hair. We apply the perfumes. We do everything that they have always done. (P1)

Some managers undertook activities that enabled people to participate in social activities such as companionship,

befriending, and accompanying them in activities outside the home. Activities intended to combat loneliness and promote social inclusion were frequently cited (**Table 4**, Quote 1). However, one manager who delivered care solely to self-funded clients felt more able to focus on companionship and social events, as illustrated below:

And then we also do trips out into the community, so we take them on different things. We've recently done a sensory farm visit. We've got an afternoon tea next week. (P9)

A few participants explained that personalised care was undertaken *with* the client with dementia rather than *done to* them, such as sharing household tasks (**Table 4**, Quote 2) or self-care, even if this were not wholly successful, as described below:

**Table 4:** Providers' perception of essentials for delivering personalised care.

Quote 1 Participant 8	And we have also acquired a community allotment....and we do bring down people with dementia. We get some really good results....because it brings back memories of whenever they could do their own gardening....and it gives them a sense of self-worth.... There is one chap....he can't formulate his words with his dementia.... But when he is at the allotment, he sings songs and he talks to us about the plants and things, which is just unbelievable. It's amazing.
Quote 2 Participant 7	...even if it's just helping them to prepare meals and I realise people with severe dementia, we couldn't..., we can spend an afternoon cooking and you can freeze these and [we] get them out because they wouldn't get them out.... But nevertheless, that's an activity which I think would be good for them to be able to do, particularly if people have always done that for themselves before.
Quote 3 Participant 1	...what we find a lot of the time is that our carers need as much, if not more, support than what the person with dementia does. We find that we look more with the carers rather than the cared for..., how we can achieve any kind of respite for them. That may just be the half hour that we're there we say to them, right, you go and get a cup of tea. Go and sit down..., let us take over for half an hour....

...if they've got the ability to still engage in caring for themselves, then we would promote that as much as we could..., if we give them a flannel to wash themselves, we know that we probably would have to go over it as well but we still give them the flannel. (P1)

The matching of care workers to clients living with dementia facilitated a more personalised approach by increasing consistency and continuity of care; this was noted by managers for both funded and self-funded clients. Managers described identifying an appropriate care worker using information from the assessment. The matching process was considered a means of encouraging a close and trusting relationship to be built up, helping to maintain the client's wellbeing:

... we've got clients with dementia who really like a certain carer and they remember the name and they remember the face, which is great. That's like, you know, a really good improvement, and you want to sort of keep that... (P2)

Whilst this was mentioned by a number of participants, some acknowledged the difficulties of this process due to inflexibility of commissioned visits, staff turnover, or logistics of arranging visit timetables.

#### Understanding wider family needs as well as individual client needs

Managers supporting LA funded clients felt it necessary to complete their own support plans to ensure clients received plans that were more individualised. Managers of privately funded clients considered that they had greater freedom to accommodate individual needs in drawing up support plans that were more flexible and responsive to social and emotional needs.

All managers sought feedback from clients or their families about their care through annual surveys, review processes, or via care workers. In many cases family needs were seen as equally important as the client's own needs and support extended to the family of their client with dementia (Table 4, Quote 3). Managers recognised when carers were struggling to cope and sought solutions to help the wider family, recognising the importance of the context for the person with dementia:

I mean we have referred sometimes for the family to go on some sort of training, we've rung the social workers; because as much as we've got training, some families, they don't seem to understand the dementia.... It's sort of supporting the family as well, isn't it? (P3)

Some participants acknowledged that, on occasion, there were unrealistic expectations from family members with regard to what the home care service could practically, or legally, do. For example, there were instances where families requested that care workers confine the individual with dementia by locking them in the house for their safety, a concern that managers occasionally felt obliged to refer to social services.

#### Collaborative and outreach activities supporting community involvement

A small number of managers referred to developing collaborations with other services, such as partnerships with voluntary organisations, community activities, and health and social care providers to support the wider family. Participant 7 described a proposed integrated model of health and social care, described as a neighbourhood team, with the possibility of working with GPs, district nurses and social workers. The team approach was considered a valuable vehicle for delivering a more coordinated service tailored to the individual and the family, accessing resources from across the community, and contributing to preventative support. By contrast, a few participants complained of poor or non-existent relationships with social workers and GPs, and of bureaucracy as impeding wider community support

And one of the other issues, that may also be working with other health professionals.... about the OT or incontinence services, and that may be not through the fault of their own..., the bureaucracy that takes over..., which obviously stops us from accessing the help quickly. (P10)

Some managers encouraged intergenerational contacts in the community through lunch clubs and other events. One participant spoke of working to build and transfer



knowledge of dementia in the wider community, illustrated in the quote below:

...we do workshops in the community..., little parts of the Dementia City & Guilds Programme that are suitable for loved ones and other people, we don't just do it for the loved ones, it was aimed at family members and loved ones. But because there wasn't that much information, we just opened it up to anybody who wanted to come along. (P5)

**Theme 2: Commissioning processes influence providers' capacity to deliver personalised care**

Prescriptive specifications constrain providers' capacity to supply personalised home care

Some care agencies supported self-funding clients only, which managers perceived as providing flexibility to allocate longer visits that could be more closely planned with the client and family. Participant 10 commented that they used a minimum of one hour to make sure 'all the psychological needs are being met during that visit' (Table 5 Quote 1). On the other hand, participants providing predominantly LA funded care considered that contracts presented tight boundaries around the practicalities of care, both in terms of length of visit and type of activities delivered. This created tensions between the requirements demanded by LAs and those that the home care agency had adopted, particularly in relation to the type of care and length of visits. Managers specifically referred to the difficulties accepting the constraints of short visits for people with dementia with complex needs. Participants whose agencies were commissioned to deliver 15 minute calls acknowledged that these were not sufficient for someone with dementia:

We don't tend to do a 15 minutes for someone with dementia, because you probably can appreciate that perhaps they wouldn't understand that you were there to give them their medication. (P3)

Contractual arrangements with LAs were usually based on assessments and care plans completed by social workers on behalf of LAs. These were described by managers using language that suggested a rigid and inflexible arrangement, such as 'prescribed', 'stipulated' and 'dictated', applying limits on what could be offered to clients and exerting pressure on care workers to adopt an over-busy and less satisfying schedule. This was expressed as problematic for the agency, as Participant 4 explained: "We often find that the thirty minutes isn't long enough, and

then we have quite a battle with local authorities to try and increase that to the hour, especially if they're on the maximum."

Sharing responsibility rather than duplicating assessment and care planning with statutory services may improve personalised care

Managers reported that the system of assessment and care planning most frequently used by LAs often led to duplication of assessment of needs. They considered that conducting their own assessment and review of the care plan was essential to the quality of care they delivered, ensuring the care could be personalised and specific to the individual client as illustrated below:

So, within 48 hours of taking on a new referral we'll arrange with the service user...and we'll meet them in the home and we'll do...basically it's a similar care plan to the council. The council just takes the time and the tasks. We put that together, but we do the person-centred planning and we put that together. (P6)

There were occasional examples of LAs introducing changes to allow care agencies to deliver care more flexibly, drawing on their understanding of the clients' needs and close involvement with people receiving care.

In the past that's been very much time and task-oriented so it would be you go in at this time, you do this, this, this and this and we're trying to get away from that now so that we can be more flexible with the time. (P7)

Increased involvement in care planning provided an opportunity to involve the family in designing care, adjusting the care package as needs changed, and maintaining relationships between assessors, commissioners, and providers. This involved high level decision making by the manager; using judgement to determine risk and identifying the need for a changed care package as illustrated by Participant 1 (Table 5, Quote 2).

**Theme 3: Preparing the workforce for delivering personalised care**

Care roles include training in dementia but relatively few specialist roles evident

There were variations in the roles that care workers were expected to assume, with some smaller agencies expect-

**Table 5: Commissioning processes influence providers' capacity to deliver personalised care.**

Quote 1 Participant 10	It's an hour per visit. So, we truly believe that to meet somebody's needs in a holistic way we have to spend more time with them. So, an hour is minimum. However, the majority of our clients with dementia, they very often receive, let's say, a couple of hours per visit so we've got enough time to make sure they are safe, they are comfortable
Quote 2 Participant 1	The only time that that gets compromised is from a safety aspect. If they're not safe then we have to look at alternatives possibly. Now that maybe either increasing the care package, extending hours, it maybe that we need to bring another service in as well, maybe a night service if we can't accommodate it or the family or social services may have to look then at outside living so residential care or extra care housing if it's available.

ing staff to perform a wide range of duties, whilst others encouraged employees to develop specialist skills in different areas. One manager had introduced specialist roles, employing a 'Dementia Champion' to deliver dementia training, to support specialist and flexible care initiatives (Table 6, Quote 1). Opinion was divided about the benefits of assigning specialist roles. Most managers stated that they trained all their staff to the same high standard so that they were equipped to deal with all types of clients regardless of their diagnosis or needs.

#### No fixed model of recruitment, training or development

Managers referred to requirements to fulfil regulations and demonstrate training and development, however, they varied in the essential characteristics they were looking for when recruiting care workers, such as personality, age, life experience and communication skills. Their greatest driver at the recruitment phase was to find individuals with 'life skills' rather than qualifications:

...I don't take qualifications into consideration when we're interviewing, because I think a personal touch is a lot better; and if they can communicate quite well with you, then you can sort of see that they can do that in somebody else's home. (P3)

Developing care workers was a strong theme in managers' discourse, however there was no single pathway or set programmes for training. Reference was made to standardised requirements to fulfil regulations and demonstrate training and development, but dementia-specific training varied widely between agencies. There were examples where dementia training was not compulsory or only comprised dementia awareness, and examples where agencies employed their own trainers delivering nationally recognised dementia care courses leading to formal qualifications, as illustrated in the contrasting quotations:

So, if staff want to go on things like that.... because it's not compulsory, we offer it just because it's always good to have a bit of extra knowledge. (P2)

We've got a trainer that works for us full time. We do do dementia training as well, separate to that five day session. We do additional courses. But every member of our staff team has been trained

in dementia care, a full day course. And then every two years we do a refresher... (P6)

Managers considered training and development as a significant cost and some were frustrated when new recruits received training and then left the organisation. Issues of funding and availability were cited as critical factors in capacity to offer job development for care workers (Table 6, Quote 2).

The importance of developing staff to be able to practice independently was evident with over half of the managers referring to staff autonomy and flexibility in deciding how to deliver care on a day-to-day basis. They encouraged staff to assume a level of independence in deciding if a client needed extra levels of support and were fully supportive of the care workers in making these changes. This was articulated as a mechanism that facilitated a more personalised approach to organising care, utilising the close relationship that the care worker had with the client and their family:

The carers actually work amongst themselves with the people that they know and are out there every day, because they know and understand what's needed and when it's needed to be able to allow them freedom to actually allow them to provide that care. And, I think that's the way forward. (P8)

#### Valuing staff encourages compassionate care

The value of the caring profession and how care workers were perceived by others in society or by television media was a recurring theme. Several participants referred to the negative reputation of the industry, particularly related to pay and conditions, such as zero hours contracts, unsocial hours, reimbursement of travel costs, and demanding work:

I think it has to do with, as I say, the not being valued and its unsociable hours, sometimes not really a pleasant task, not very well-rewarded financially, so why would you do it? (P7)

The importance of a specific understanding of the different demands that dementia can make on staff was emphasised in some cases. Participant 10 noted the general lack of understanding of dementia in the community and the consequent challenge of recruiting and retaining good quality care workers to support clients with dementia:

**Table 6:** Different approaches to workforce development.

Quote 1 Participant 6	We had a dementia champion that came and worked for us on a part time basis on an 18 month contract ..., and he put together our dementia angels. So, I think we had eight carers and they were trained over the course of three days. So, we've got the senior carers and we've got our dementia angels. But they're our champions really. So, if we are struggling with a service user with dementia then we talk to them. They're the most knowledgeable. We usually send them out to meet family members and they can be quite supportive in that way. They're a really enthusiastic team.
Quote 2 Participant 7	So, accessing dementia training is difficult. The local authority now runs a Level 2 qualification with its distance learning. And we use that, but dementia care is part of our mandatory training, but it's very general. And as I say, I would like it to be more...I'd like to be able to access more than we can at the moment, but I think that's a pipedream.

...they are caregivers who...or people who want to be our caregivers, that simply are not prepared to support clients with dementia, that there is still loads of stigma, there is still loads of stereotypes..., and I think that very often puts people off, and it is a shame. (P10)

## Discussion

This study explored the experiences and views of home care managers of delivering care for people with dementia living at home, in relation to both LA commissioned and privately funded care in England during a period of austerity (Power, 2014; Bottery et al., 2018). The rich data generated from the qualitative interviews with home care managers representing both small and large-scale businesses, has given a detailed picture of home care provision for people with dementia. The three themes identified from the managers' interviews highlighted a number of issues relevant to the debate about the role of home care agencies in the delivery of personalised care. These are discussed as four distinct issues related to (i) prioritising social and emotional support for people living with dementia *and* their family to achieve wellbeing and social goals (from Theme 1); (ii) maintaining and facilitating inclusion of clients in community activities (from Theme 1); (iii) the constraints imposed by local authority processes and limitations (from Theme 2); and (iv) developing the skills and status of care workers, with particular focus on understanding dementia (from Theme 3).

### ***Prioritising social and emotional support for people living with dementia and their family to achieve wellbeing and social goals***

Managers considered that social and emotional support were essential and valued elements of the care role for people with dementia. However, involving the client in more diverse social activities was more frequently reported as an option for those who funded their own care. In contrast, activities to support LA funded clients appeared more functional, such as accompanying the client to a hospital visit. Delivering social and emotional support for people with dementia also depended on the quality of the relationship between the individual receiving care and the care worker, as well as contracts that were flexible and gave sufficient time to respond to changeable needs. There were accounts from many managers of supporting the client's informal carer, acting as a confidante, negotiating delicate situations with families, and establishing familiar and trusting relationships. This is in keeping with international research that emphasises the importance of relationship-centred care (Adams & Gardiner, 2005; Dupuis et al., 2012), conceptualising it as an essential building block for personalised care.

### ***Maintaining and facilitating inclusion of clients in community activities***

Those overseeing the delivery of home care perceived this as more than delivering an individualised care plan, implicitly acknowledging the importance of enabling

social inclusion. As publicly funded care compared less favourably to self-funded care in terms of the availability of time for the individual, the role of 'social health' (Huber et al., 2011) may be considered as an underestimated opportunity for prevention and management of dementia (Vernooij-Dasson & Jeon, 2016). Such opportunities for social and emotional needs and activities for wellbeing were rarely articulated as part of LA contracted care, in spite of the potential for improving functional abilities and promoting well-being (Jasper et al., 2019). Using home care hours more flexibly and responsively, shaped by home care agencies and their staff, together with clients, may encourage a more satisfactory use of existing resources (Bracken-Scally et al., 2018; Alderwick, Tallack, & Watt, 2019; Bottery, 2019).

The inclusion of people with dementia in community activities may also contribute to positive social and emotional outcomes. The findings suggest that managers sought innovative ways to help individuals and their families form connections with the community. This included building an understanding of dementia within the wider society through accessible training and enabling anyone in a local community to maximise an individual's independence and wellbeing in spite of their cognitive decline. Sharing knowledge with families and society, running intergenerational activities, and forming mutually rewarding partnerships with community groups illustrated home care providers' aspirations to establish themselves as more than purely care providers. Such a role aligns with NICE quality standards (NICE, 2019), which endorse creating links between local communities and older people living at home.

### ***The constraints imposed by local authority processes and limitations***

LA commissioning arrangements imposed notable constraints on the form and focus of services delivered by home care agencies. Managers delivering care for LAs frequently conducted their own assessment in order to personalise care, thus duplicating the LA assessment. Since the Care Act (2014), assessment functions that were previously the remit of LAs may be delegated to non-statutory organisations, but little evidence existed to suggest this was routinely happening. Whilst LAs are responsible for a financial assessment to determine eligibility for care, there may be a case for more clearly creating boundaries between assessment for eligibility of funded care and assessment for meeting specific needs, based on clients' preferred outcomes as happens in other jurisdictions (Campbell et al., 2016; Australian Government, 2017). The latter could then potentially become the primary responsibility of the home care agency. Managers were also keen to reform the time and task component, an approach which government guidance had sought to reform (Cm 8378, 2012). Many disliked its rigid format and restricted focus that could hinder person-centred care, a viewpoint reported elsewhere by home care agencies, clients, and care workers (Equality and Human Rights Commission, 2011; Jefferson et al., 2018). The imperative to commission



for better outcomes (Local Government Association, 2015; Bolton, 2016) could be achieved more efficiently through a partnership model between home care agencies and commissioners (Davies et al., 2020), enabling agencies to be the mediators of commissioning for outcomes.

### ***Developing the skills and status of care workers with particular focus on understanding dementia***

Managers did not markedly distinguish between specialist and generic care, but rather they adapted their services to deliver personalised care that suited those living with dementia. However, there were examples of specialist teams that were more equipped to support the needs of people with dementia. Specialist support for people with dementia, whether articulated or implied by managers, depended on developing the skills of care workers through training. The role and status of care workers was a recurrent issue with managers who considered that care staff were undervalued by society, compounded by a public lack of knowledge about dementia, and a perceived lack of respect. Qualities of emotional intelligence (Schneider et al., 2019) such as excellent communication skills, social skills, and compassionate natures were actively sought by managers during recruitment. Autonomy and independence were encouraged by some managers, permitting care workers to use their initiative to provide care more flexibly for people with dementia. Home care workers in a recent study affirmed that being flexible and adaptable was a vital influence on good dementia care (Abrams et al., 2019). Life skills were preferred over qualifications in new recruits, reflecting evidence of low levels of relevant qualifications in care workers (Hussein & Manthorpe, 2012; SFC, 2018). The cost, availability, and variability of dementia training were sources of concern, with provision of training to home care workers varying widely between agencies. This issue has been prioritised at the national level in England (Health Education England, 2018a) with the creation of consistent standards and accompanying resources (Health Education England, 2018b) contributing to staff development.

There are three limitations to the study which require consideration. First, although it presents the views of a range of agencies, managers volunteered to participate and may have represented successful and motivated organisations. Second, managers may have been influenced by social desirability bias, thus portraying their agencies in a positive light. Third, home care workers' views and experiences were not reflected in this study and may have differed from those of managers. Nevertheless, the views expressed explicitly, and the implicit notions revealed in the examples and illustrations presented by managers, offer valuable insights into the challenges of providing personalised home care for people with dementia.

### **Conclusion**

According to home care managers, providing personalised care, whether specialist or generic provision, depends on delivering a responsive approach that includes supporting the social and emotional needs of individuals and their

families. To achieve this, home care agencies need to be acknowledged as capable contributors in assessing and adapting care according to the variable care needs of people with dementia. The impact of long-term austerity and underfunding of social care limits the scope of home care providers delivering services on behalf of local authorities, potentially magnifying the differences between those with self-funded care and those receiving LA support only. The capacity to deliver personalised care for people living with dementia also depends on a skilled workforce, able to understand the implications of dementia and to combine this with responsive and compassionate care. The COVID pandemic has heightened the importance of understanding provider capacity and the need for commissioners and policy makers to ensure a sustainable workforce in domiciliary social care. There is clearly a need to explore the impact of different approaches to commissioning upon providers, building on areas identified in Themes 2 and 3 of the present study, namely the commissioning process and workforce. Such an enquiry could employ a case study approach examining the complex factors at work in both providers and commissioners' environments and the ways they are involved (Eisenhardt, 1989; Eisenhardt and Graebner, 2007; Gehman et al., 2018).

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The authors have no competing interests to declare.

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